Community-University Research Partnerships: Devising a Model for Ethical Engagement

Linda Silka, Paulette Renault-Caragianes

Abstract

Profound changes taking place in communities and in universities are bringing researchers and community members new opportunities for joint research endeavors and new problems that must be resolved. In such partnerships, questions about shared decision making—about the ethics of collaboration arise at every stage: Who decides which problems are worthy of study? Who decides how the research will be conducted? Who owns the data once they are collected? This article summarizes a research cycle model that integrates these disparate issues within a larger framework that ties them to steps in the research process. Rather than prescribing a predetermined set of answers, this model encourages researchers and community members to cooperatively construct solutions appropriate to specific contexts and situations. It can be used to build sustainable research partnerships that generate multiple investigations and a variety of applications benefiting both campus and community.

Introduction

Research collaboration is one of the important forms of engagement that universities can offer to communities. Although universities are particularly rich in resources for research, such capacities have often not been used effectively in community partnerships (Kellogg Commission 1999; Lerner and Simon 1998; Nyden 2005). A concern at the forefront of many discussions is how the research strengths of universities can be integrated more fully into partnerships with communities (Brugge and Hynes 2005; Israel et al. 1998; Sclove, Scammell, and Holland 1998; Walshok 1995).

It is particularly timely for communities and universities to examine how they will go forward in working together (Holzner and Munro 2005; Silka 2002). Universities are in a period of rapid change, with increased emphasis on community partnerships, engagement, and outreach (Holland 2005; Maurrasse 2001). And communities across the country are experiencing rapid changes that create new challenges and bring into question the viability of past practices. Many communities, for example, are finding themselves increasingly diverse as immigration and other changes alter

the demographics of their neighborhoods (Migration Policy Institute 2004; HUD 1999). Greatly needed are research partnerships that will bring the resources of universities together with the most pressing issues communities now face.

Well-intentioned as calls for collaboration may be, communities and campuses rarely come to such research collaborations with "open arms." Past experience has pointed to difficulties that can arise when researchers and communities attempt to work together (Nyden and Wiewel 1992; Silka 1999; Strand et al. 2003). Community-university research partnerships, for example, often bring powerful university scholars (e.g., researchers with international reputations, sizable grants, and extensive publications) into involvement with those in the community who are the most disempowered (e.g., newly arrived immigrants). In areas of study such as health dispari-

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ties and environmental justice, for example, funders are now calling for researchers to set up partnerships to investigate the health disparities found in poor urban communities (Green and Mercer 2001; Shepard et al. 2002). Accomplished researchers adept at securing research funding seek out poor communities where these health disparities can be studied in their purest form. Too often researchers arrive at these

communities with research plans already fixed and stay only as long as it takes to collect data to test their preconceived hypotheses (*Brugge and Hynes 2005*). The differences in power at the heart of these interactions often make it difficult for community members to have a voice in the research.

These problems in community-university research partnerships were vividly captured by Loretta Jones (2006) in her keynote address to the Community Campus Partnerships for Health (CCPH) Conference, the conference at which the model described here was presented. Jones likened community-campus research partnerships to a bus journey in which people get on and off the bus at different times and use the bus to go to different places. She pointed out that researchers and community members often envision vastly different destinations for their "journey": the researchers might be focused on science, whereas the community might be intent on ensuring that the findings result in more than an academic publication. These images comparing partnerships to bus

journeys resonated with CCPH conference attendees, almost all of whom were involved in community-campus research partnerships. Attendees adopted the metaphor of the shared bus journey as a kind of shorthand for the problems they struggled with in their own collaborations. Conference attendees noted the problems that result from a lack of true collaboration. Researchers have already decided which issue will be studied before consulting the community; they have failed to ask communities how they thought the problem should be investigated; and they have focused only on studying a problem, with no attention to the findings' relevance for its solution. The paucity of benefits from such one-sided "collaboration" has reduced the likelihood that communities will seek to engage in research with universities again in the future.

The Development of a Research Cycle Model of Partnership Engagement

It has become clear that at every step of the research process, collaborations raise difficult issues. These issues are prompting a reenvisioning of research engagement in community-university partnerships (see CIREEH 2005). Attention is turning to practices, like those used in community-based participatory research, that move beyond the single studies and limited-time interactions that were the primary means by which university researchers engaged with communities. A question now at the forefront is how to move beyond existing guidelines (for example, institutional review board practices) that were set up to handle one-time interactions and were not designed to provide ethical guidance to the research partnerships that are becoming more common (Brugge and Hynes 2005; CIREEH 2005). Efforts are being made to develop models of ethical research engagement that address the kinds of partnership issues that emerge at every step (Boyer et al. 2005; Brown and Vega 1996), from conceiving the research to using the findings (Brugge and Hynes 2005).

At the University of Massachusetts Lowell, our own experiences with the challenges of multiyear community-university research partnerships very much mirror those that others pointed to at the conference. Many of our partnerships have taken place in Lowell, Massachusetts, a rapidly changing city that is now home to the second-largest Cambodian community in the country as well as to large African, Central American, and South American immigrant communities. Over the last two decades the university has entered into research partnerships funded by various foundations as well as Centers for Disease Control (CDC), Environmental Protection Agency (EPA), the U.S. Department of Housing and Urban Development (HUD), the National Institute of Environmental Health Sciences (NIEHS), the U.S. Department of Education (DOE), and the National Science Foundation (NSF). These partnerships have brought immigrant communities, university faculty, and other partners together to focus on education, environment, health, and housing. Across these very different partnerships, the need to address ethical dilemmas at different stages repeatedly emerged. Like our colleagues across the country involved in community-university research partnerships, we found ourselves struggling to make sense of our experiences in the absence of a framework or model that encapsulates the stages of community-university research partnerships and highlights the ethical dilemmas tied to each. A framework was needed to bring coherence to

the many, many issues that arise within extended research relationships and to help partnerships learn from others' experiences without starting from scratch each time a new set of partners came together.

A desirable framework would provide a straightforward yet generative model that calls attention to ethical dilemmas and aligns these dilemmas with particular steps in the process of partnership, yet does not dictate how individual partnerships "...it is important not to create a set of lockstep rules that give the false hope that simply following some preset formula will ensure partnership success."

should resolve these dilemmas. Work toward a model to capture some of these common lessons needs to address four aims: (1) to integrate the disparate steps in partnerships (e.g., which problem will be studied or how the results will be used); (2) to create some kind of rubric such as a "cycle" that highlights the fact that research partnerships move forward over time; (3) to show that research ethics is not separate from the research steps, but instead is integral to each; and (4) to create a model that assists people in anticipating difficulties likely to arise in their partnership. However, it is important not to create a set of lockstep rules that give the false hope that simply following some preset formula will ensure partnership success. A framework should encourage partnerships to productively assess their dilemmas while requiring that each partnership generate its own solutions appropriate to its context.

Research partnerships, when successful, generate multiple investigations and applications that aggregate over time: a study

is decided upon by partners, results are produced and jointly interpreted, findings are applied and published, and then a new study or new set of applications begins that builds on the earlier work. We have found that the use of a simple graphic works well to situate research stages within this cycle (see figure 1 for the graphic and table 1 for illustrative issues that arise throughout a research cycle). At each point in the cycle, there are important issues of partnership that must be addressed, and what matters is not just "what" but "when." If the community is invited in after researchers have determined the hypothesis, for example, there will be few opportunities for community knowledge to shape the cycle of research, and thus less likelihood that community members will benefit from the results

We use the model to focus attention on issues (see table 1) that partnerships encounter in a cycle of research that they generally would not encounter in a brief, one-shot study. At the start of a research cycle, for example, community groups often begin with a problem they want solved, whereas the researchers start out with a research hypothesis. Often the goal for the researchers is a research publication, and the goal for the community partner is to apply findings to solve the problem. The model points to the need to bring the two together; in other words, to reframe the hypothesis so that the findings satisfy the requirements of both "good science" and "good problem solving." By tying together an analysis of a problem with its possible solution, the model suggests how to reframe difficult issues. In the area of environmental health, for example, a simple focus on testing a hypothesis about whether a particular chemical poses an environmental health risk rarely meets community needs. Such a focus may answer a research question but fails to provide guidance for what communities should do to eliminate exposure to the chemical. The model can serve as a way for partnerships to think through concerns that emerge at one stage of a collaboration and have the potential to cause a cascade of disruptive effects.

An Illustrative Example of Use of the Research Cycle in **Practice**

We have found this framework helpful in our own work in Lowell, Massachusetts, and we are frequently asked to share these ideas with others around the country at workshops, presentations, and courses (CIREEH 2005). Consider how we have used the model in Lowell. The framework shows us where we might need to focus our efforts, such as ensuring that all of the steps in a research cycle are completed. In some cases, various researchers keep repeating

Table 1: Examples of Issues at Initial, Middle, and Final Stages in Partnership Research Cycles*

Who decides on the research agenda and research questions?

Researchers and their community partners often disagree about who should set the research agenda. Researchers with a detailed background in a particular area (for example, the causes of lead poisoning in children) may assert that they should make the decisions. Community members aware of the health costs to the community of a health problem may assert that they should make the decisions about the research agenda. How can these differences be negotiated so that the rigorous research carried out is helpful in addressing problems and in answering basic research questions?

Will the focus be on solving a problem or understanding the problem at a basic level? Communities and researchers often have different goals in collecting data. Communities may see a problem that is devastating their children and want to address it. Researchers are often trained to try to get to the bottom of things and to leave no alternative explanation in place that could account for a problem. These differences in goals can affect the foundation of a partnership.

Is the purpose of the research to gain general knowledge (with individual "subjects" seen only as a means to that knowledge) or is the purpose to gain knowledge intended to be useful to those who participate in the research? Many researchers talk about individual communities as "laboratories." For researchers, a community near their university is a place to test out hypotheses, but those researchers might have relatively little interest in ameliorating problems in that same community. Community members may be concerned not about the generalizability of the findings but whether they speak directly to problems in their community and what should be done.

What methods will be used to gather information? Who decides how information will be gathered to answer the research question? How are decisions made about what's credible?

When is enough known? When has enough research been done? Many underserved communities have experienced being "studied to death." They are studied repeatedly, but with little to show in the way of benefits to the community. How does one decide that the information collected justifies focusing on interventions as opposed to collecting more

data? Who makes this decision?

Initial Stages

Who owns the data? Increasingly, questions are emerging about who owns these data. If studies investigate contamination levels of lead in the blood of a community's young children, does the community own the data? The researcher? The partnership?

Should the community be able to approve research findings before they are submitted for publication? Many researchers struggle with calls for the community to give their approval before findings can be submitted for publication. Communities are often puzzled that researchers do not understand the need for careful consideration of how results are described and how the community is portrayed. Researchers sometimes see the issue in terms of prior restraint of publication, whereas communities sometimes see the issue as one of respect and power sharing.

The press of time: Everyone involved in research partnerships worries about how long research takes, but partners may differ on when delays seem reasonable. For example, researchers worry about how long it takes to get a community on board in planning for research. Many researchers say that as a consequence they can't afford to get involved in community-researcher partnerships. On the other hand, researchers find delays acceptable if they occur when another study is needed, while awaiting institutional review board approval, or during a long period of review for publication. Both groups talk about being frustrated by how long things take, but they differ in which delays are matters for concern.

Source: Online workshop "Building Strong Community University Research Partnerships" in Silka 2003

the beginning stages of the cycle and never quite get to application of the findings. Many researchers, for example, are interested in the trauma experienced by Cambodians and other refugees from war-torn countries. Researchers arrive in Lowell and ask questions designed to probe the most troubling aspects of Cambodian history, such as the impact of war trauma. The first wave of researchers then disappears, perhaps to publish the results but often not. Soon thereafter, another wave of researchers arrives and asks largely the same questions. This continues with one team of researchers following another, often oblivious to previous efforts. In such instances, the continued investigation of community problems leads to little amelioration and the intervention stage of the research cycle is never reached. A theme that has repeatedly surfaced in Lowell is the discrepancy between the considerable volume of research being directed at the community and the sparse accumulation of knowledge that truly benefits the community. As one community leader in Lowell put it, another dissertation student has achieved the Ph.D.—but how has the community benefited?

Researchers are taught to think that the publication of findings is the natural ending to a cycle of research. Findings are published and thereby disseminated. But research in communities sheds light on how ill-suited academic journals are to carry the burden of shared, useful knowledge. Although journals serve to facilitate the accumulation of knowledge, the pace with which they disseminate information is often too slow to help communities avoid the "same study" syndrome. That journals are designed to serve a gate-keeping function adds to the problem: very few studies actually reach publication. Journals are thus poorly suited for meeting the community's need for information about the full range of activities that take place between scientists and community members, including false starts and dead ends.

By thinking in terms of research cycles as opposed to one-shot studies, partnerships such as ours have begun looking for other ways to retain shared knowledge, perhaps through something that might be called a community repository of knowledge (Silka 2003). Such a repository could be easily available to the community and could include information about which studies have already been undertaken in the community and what these studies have uncovered. Community repositories of knowledge would have the potential to make communities less dependent on the forms of knowledge accumulation aimed at scientists or organized in terms of scientists' frameworks. Communities would be freer to arrange knowledge to meet their own problem-solving needs. In the Lowell area, we have begun to look together at how refugee and immigrant communities gather, store, and share different kinds of knowledge and how the storing of research information within communityuniversity partnerships could incorporate those methods. The result could be new ways to close the gap between researchers and the community.

We have found this research cycle model provides useful guidance on a variety of issues confronting research partnerships: Who owns the data and when should these issues of ownership be considered? Given that studies often target difficult issues, what should partnerships do when results reflect badly on the community, and when should these issues be negotiated within a partnership? Who speaks for the community, and how should research partnerships handle the fact that communities not infrequently undergo considerable turnover in leadership and thus the same people will not always be on the other side of the table throughout the life of a research partnership? These and many other issues can be anticipated within a model that views the research enterprise as ongoing and charged with difficult issues.

Teaching the Model

The model described throughout this article lends itself to use within partnerships at all of their stages: initial, middle, and later stages. And partnerships can learn about the model through different types of presentations. An introduction to the topic lends itself to workshop presentations of as little as a few hours' duration, as at the 2006 CCPH conference. The model also adapts well to extended teaching settings: at UML we have built an entire course around this research cycle approach to community-university partnerships. Silka (2006) describes the development of the face-toface course and how it was then redesigned for online teaching so that people in research partnerships around the United States might be reached. A unique feature of the full-semester course (both traditional and online) was how we attempted to "practice what we preached" by creating a free community-university workshop facilitated by the class and designed to provide people with opportunities to explore the model's usefulness through examples and illustrations. In the case of the online course, we created a oneday online workshop for partnership practitioners from the United States and other countries, who then had opportunities to analyze the examples online.

Conclusion: Looking to the Future

An emphasis on community-university research partnerships has implications for institutional policies within higher education. This approach may be used by individual faculty to anticipate challenges in their personal engagement in partnerships. The research cycle approach also points to the possible need for broader institutional changes, such as reforms in institutional review boards and in tenure and promotion practices. The ways that current institutional procedures may thwart community-campus research partnerships are coming under increased scrutiny as many universities undergo the largest faculty transition in decades. (UML, for example, is currently undergoing the greatest faculty turnover since its inception.) The large cohort of the 1960s faculty is being lost to retirement, and their younger replacements often hold different perspectives on the value of engagement. The search for continuity in partnerships is made all the more challenging by the changes reshaping UML and the many other universities in the process of replacing their retiring "baby boomer" faculty (Clark 2004; Hutchings, Huber, and Golde 2006). These new faculty are in the midst of establishing what are likely to be their career-long

approaches to research, putting universities in a unique position to adopt procedures and practices that encourage effective community research engagement.

HUD's Office of University Partnerships (http://www.oup.org) is one source of guidance for developing these institutional supports for partnerships. This HUD office recently published a volume on applied research and partnerships (Silka 2005). Community-Campus Partnerships for Health is another major resource (available at http://depts.washington.edu/ccph/partnerships.html). Other sources include National Institute of Environmental Health Sciences (O'Fallon, Tyson, and Dearry 2000), Campus Compact (2006), and Carnegie Foundation for the Advancement for Teaching,

"If decoupled from the knowledge function of universities, engagement will remain at risk whenever higher education resources are in short supply..." with its emphasis on university indicators for community engagement (http://www.carnegiefoundation.org). Groundbreaking books on community-university research partnerships are also available (*Lerner and Simon 1998; Minkler and Wallerstein 2002*).

Throughout this article we have noted that both communities and universities are undergoing rapid change, making a focus on partnership and engagement timely. If the research strengths of universities are

to be brought fully into the engagement arena, a guide such as the research cycle model will be needed to navigate the path from freestanding, academia-focused studies directed by universities to full-fledged partnerships among equals. Ultimately, the importance of linking engagement to research should not be underestimated. If decoupled from the knowledge function of universities, engagement will remain at risk whenever higher education resources are in short supply and universities begin jettisoning activities seen as peripheral to their core mission. Work is now under way at many universities to find ways to link to core missions and make partnerships easier to achieve and less problem prone. This article has outlined some of the ways that an ethic of research engagement will be integral to the success of this endeavor.

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About the Authors

- Linda Silka earned her Ph.D. in social psychology from the University of Kansas. She is currently a professor in the Department of Regional Economic and Social Development at the University of Massachusetts Lowell. Dr. Silka is director of the Center for Family, Work, and Community at the University, and codirector of the University's Community Outreach Partnership Center. Her research and teaching interests include community capacity-building, program evaluation, refugee and immigrant leadership, community-university partnerships, community mapping and geographic information systems, strategic planning, needs assessment, and community conflict resolution. Dr. Silka has been active in Community-Campus Partnerships for Health, is one of the founders of Researchethics.org, and has been a practicing community-based researcher for the past twenty-five years.
- Paulette Renault-Caragianes earned her master's degree in public health from Suffolk University. She directs community partnership programs at Lowell Community Health Center. Ms. Renault-Caragianes oversees school-based health clinics in Lowell and has been a leader in multiyear environmental health and occupational health partnerships and collaborations that bring together refugee and immigrant community members, health providers, and university researchers. She serves on the University of Massachusetts Lowell Community-University Advisory Board and is a Community Member on the University of Massachusetts Lowell Institutional Review Board. Ms. Renault-Caragianes has been widely recognized for her community leadership and activism throughout Lowell on teen leadership, community development, health partnerships, and neighborhood improvement.